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Why I Gave Away My DNA For Free

We can all be information altruists!

by Theresa Fisher (<https://woollymag.com/author/theresa>)

Art credit: Twisha Patni

I came into the world weighing 7 pounds, 6 ounces, with a few strands of hair and, according to a handful of genetics studies, a considerably elevated risk of developing an aggressive form of prostate cancer. At least, that's what I learned last week from exploring the results of genetic testing I'd done recently. This information almost made me retreat into a dark, fatalistic crawl space in my mind. Then I remembered something: I don't have a prostate.



I also knew better than to take the results of consumer-grade genetic testing with anything besides a huge, shaker-clogging grain of salt. Because these tests are just for fun!, as the companies that make them are required to state. It's *fun!*, you see, for me to discover that my genetic blueprint indicates "highly below average intelligence." On top of that, one genetic-testing app got my blood type wrong, which struck me as a reliability red-flag.

But even though most of what I'd learned from getting my DNA mapped out was unreliable or useless or anxiety-producing, or some combination of all three, I didn't regret doing it. That's because it let me do something for the greater good: donate my genetic data.

In genomics — the branch of genetics concerned with studying the whole genome, rather than individual genes — breakthroughs are more likely when researchers have access to a bigger and more diverse bank of genetic data. There's not much I can do with intel on my prostate-cancer-prone genes to help myself, but who knows what scientists can do with the intel to help other people. You might call me naive or simple or even a shill for Big Genome. But what I really am, I discovered, is an information altruist. (More on this later.)

A fleet of personal genomics companies, (https://isogg.org/wiki/List_of_DNA_testing_companies) each with its own focus, shtick, and price point, has cropped up over the past decade. The genetic tests they offer are supposed to be recreational. Or that's what the FDA makes companies claim, in order to avoid misleading people into making important and potentially expensive health-related decisions based on results that aren't as meaningful as they might seem.

I first thought about venturing into genetic testing about 8 years ago, when I heard that my friend's friend's dad discovered he had the gene that makes cilantro taste like soap (rather than the fresh ambrosia I taste). But prices were higher back then. Plus, I thought I'd just end up tangoing with hypochondria. I am, after all, neurotic enough to see the word "cancer" and temporarily forget there's no prostate down there.



Then, this past summer, a new genetic-testing startup called Gencove (<https://gencove.com/>)

reached out to me, offering to sequence my genome for free. What the hell, I figured, and took the

plunge. Gencove is the passion project of its CEO, Joe Pickrell, a former computational geneticist at Columbia University. Pickrell defected to the spit-kit industry after the discovery of his own inherited disorder alerted him to the need for more accessible, easy-to-interpret genetic data.

A few weeks after I handed over a vial of my saliva, Gencove sent me the goods, meaning raw genetic data files to use however I saw fit, plus three reports — on my ancestry, microbiome, and chronotype.

My ancestry report came in the form of a colorful map illustrating how much of me comes from which regions of the world. The colorful map also made it clear where I don't come from: the

My microbiome report broke down how much of which microorganisms live inside me. It said I have 32 percent bacteroidetes, which is ... cool? Ordinary? A harbinger of doom? I had no idea. So I asked Joseph Petrosino, a microbiome researcher and professor at the Baylor College of Medicine, to take a look at my report.

"All I can say here from your saliva sample is that the phyla detected are all expected and are generally at the ratios one would anticipate," Petrosino told me via email. "It's like trying to figure out details about you by looking back 4 or 5 generations on your family tree."

My chronotype report revealed that I'm a night owl, with "weak confidence." Chronotype is heavily influenced by genetics (<https://vanwinkles.com/how-much-should-you-challenge-your-chronotype-a-little-bit>) (as well as age and light). Gencove is the only company to offer a chronotype test, which tells you your probability of being an "up and at 'em" type, based on the findings of a 20,000-ish-person study. The chronotype feature is neat and novel and not something to take too seriously.

Overall, the three reports weren't exactly a captivating window into the genes and guts of Theresa Fisher.



I wondered how other people felt about their experiences with personal genomics. So I talked to 10 people who'd gotten health-related information from genetic tests (in addition to ancestry for me) analysis, for the most part). Eight of them said they did it out of curiosity. They were typically neither disappointed in, nor fascinated by, their results.

Wellness) Even though genetic-testing consumers tend to be fairly well-informed about what they're getting themselves into, research suggests they're still likely to believe their tests are more clinically relevant than they are. In one 2012 study, researchers at the University of Minnesota School of Public Health surveyed "early adopters" of personal genomics, and found that 92 percent of them planned to show their spit-kit test results to their physicians. Of course, that feeling doesn't mean their physicians could do much, or anything, with the results: In a different survey of spit-kit consumers who shared their results with doctors, most people said they were not satisfied with their doctors' responses.

both) (But I should still call my doctor after hours to tell her that my "phyla are generally at the ratios one would anticipate," right?)

I also spoke to a few people who said they'd never willingly give up their genetic data, for fear of who might access it and for what purpose. Initially, these sorts of concerns struck me as overly paranoid, conspiratorial nonsense. After all, genetic-testing companies have privacy policies in place. Not to mention, a 2008 federal act called GINA prohibits health insurance companies and employers from using genetic data to make decisions about coverage or employment.

But then I did some research and decided that it's not entirely unreasonable to be paranoid about genetic data becoming non-anonymous, an issue known as re-identification, or winding up in the wrong hands.

So, if spit-kit health results aren't that meaningful for most people, and if there's inherently some risk of genetic data being used in undesirable ways, then what's the point of dabbling in personal genomics, especially for a neurotic person like me?



I directed my question back to Pickrell. Novelty, he said, is a big draw. In my experience, novelty wears thin quickly.

Pickrell offered another explanation. Genetic-testing results might have limited value now, but the findings behind Gencove could potentially use the chronotype data they collect, for instance, to find new genetic variants associated with sleep. (Variants are tiny DNA mutations that differentiate our otherwise largely identical genomes.)

The potential for discovering new variants is a big part of Gencove's whole *thing*. Gencove uses a technique called genome sequencing, which entails mapping out a chunk of the genome, or even the whole thing, point by point. Most other companies do genotyping, which is sort of like DNA spot-checking — a company will zero in on, say, 600,000 (out of 3 billion) points on the genome.

Genotyping traditionally costs much less than sequencing, but Gencove found a way to sequence about 10 percent of the genome on the cheap (and use an algorithm to fill in the rest of it). Genotyping works well, Pickrell says, if you want to look at predetermined variants. But if you want to find new ones associated with chronotype (or anything else), then you'd want to cover more territory.

In genome sequencing, the larger and more diverse the database is, the more it becomes.

Plus, Pickrell says, customers can take their data and give it to research projects focused on learning about the genetic basis of all sorts of traits and conditions.

This explanation appealed to me. If getting my genome sequenced wasn't just about me, then I could justify uninteresting or even upsetting test results as secondary to the goal of contributing to science. In some sense, genetic testing was altruistic. Or, I decided, it could be.

Apparently, there's a name for people who share this philosophy: information altruists. Two doctors coined the term in 2005, as a way to describe people who are ideally suited to participate in personal genomics. Information altruists, they determined, would be most likely to accept the



Genetic-testing companies have emphasized the altruism inherent in personal genomics since the industry emerged. Of course, they also presumably want to get their hands on our genomes for reasons that have little to do with humanity and everything to do with their bottom lines. I fully acknowledge this. But I still believe in information altruism.

So, I set out to translate theory into practice. I took my raw genetic data from Gencove and shared it on Open Humans (<https://www.openhumans.org>), an online community that lets users donate their genetic data to specific research projects, as well as sign it over to the public domain. If users opt to do the latter, Open Humans makes it clear their privacy will not be assured. They even require users to take a quiz to prove they understand that their genome is up for grabs and could be used in all sorts of unknowable and even illegal ways. This made me sweat. But I proceeded. All in a day for an information altruist.

Once I'd given up ownership over my genetic data, I decided to see what else I could learn about myself. Through the Gencove portal, I made my way to other websites, where I could order more genetic reports.

A site called Promethease (<https://promethease.com/ondemandagreed>) applied the findings of more than 2,000 genetic studies to my data and generated a report with all sorts of insights. This is where I learned about my prostate cancer predisposition, as well as dozens of other negative and positive, and sometimes contradictory, predictions. Some results were validating — 100 years old, here I come. Others were dispiriting, like the outcome of the “Alzheimer’s gene” test I swore I wouldn’t look at. And others were unequivocally wrong. (Hey, Promethease, I’m O-, not O+.)

I figured I'd go crazy trying to create a realistic composite of myself and my health. So, instead, I cherry-picked the results I wanted to believe, and turned myself into a buxom, blue-eyed endurance athlete with a heart and memory of steel.



I also uploaded my data to an app store for genetic tests, called Geneplaza

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(<https://www.geneplaza.com/>), where I learned that, based on 52 genetic variants associated with

intelligence, my IQ is “highly below average.”

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But that’s okay, because this is all for *fun!* And even if I don’t find it fun to worry about my meager intellectual capabilities, then it’s all for science.

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The relevant altruistic act here was donating my genome, not my money. But I kept coming back to the fact that Gencove waived my fee. Did that make my donation any less altruistic? I wasn’t sure. Ethics are confusing! I wanted to hit the sack without this question weighing on my mind.

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So, I decided to take the \$60 that Gencove didn’t charge me and pay it forward to Give Directly (<https://www.givewell.org/charities/give-directly>), which distributes cash to very poor individuals

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in Kenya and Uganda. And then I dedicated *that* donation to Gencove.

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One more thing: Please don’t steal my genome.

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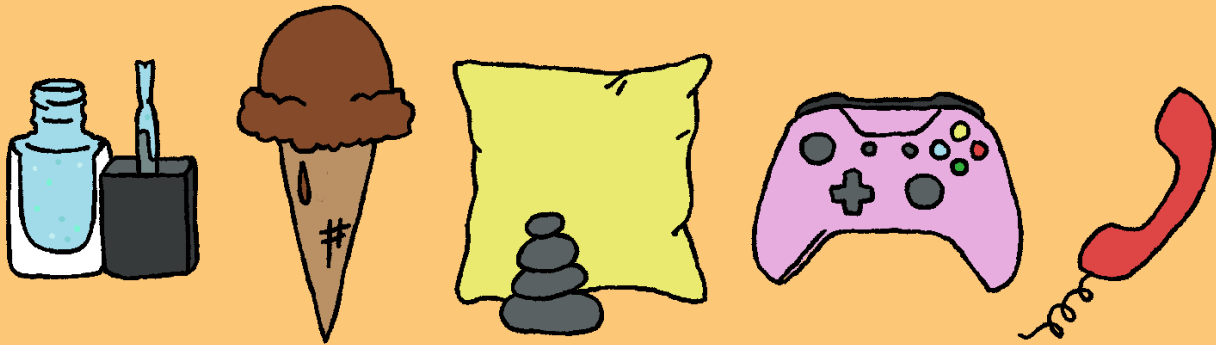
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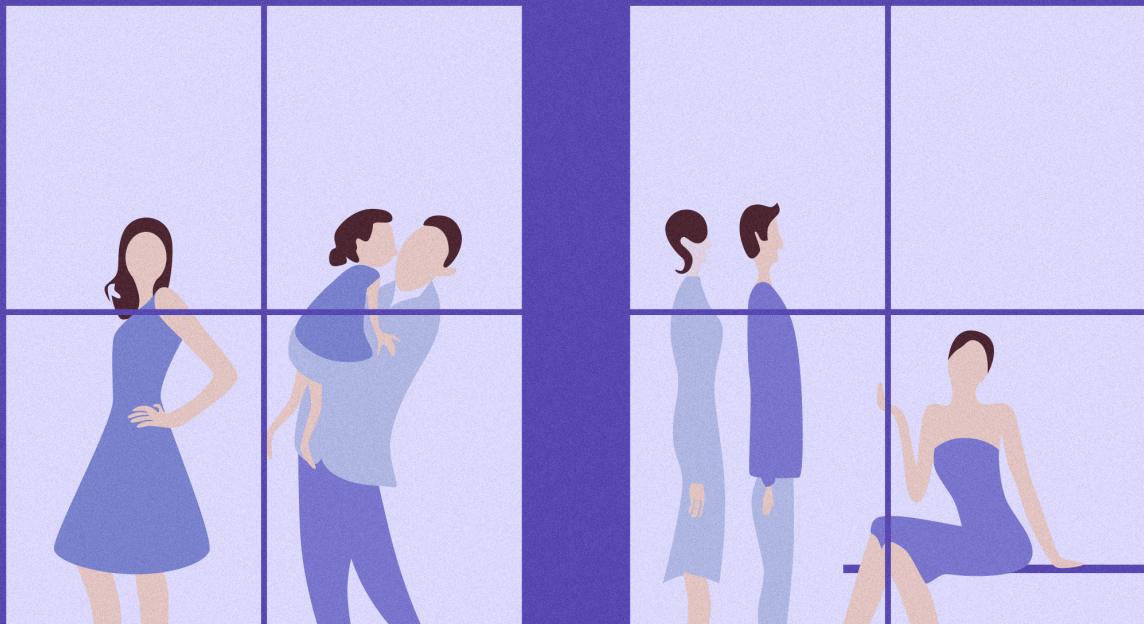
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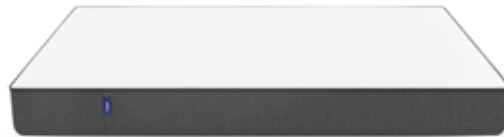


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